Nevada Rare Disease Advisory Council (NV RDAC)
2025 Awareness & Needs Assessment Campaign – Proposal for Council Approval
Duration: 12 Weeks | Platforms: LinkedIn, Facebook, Email Outreach, Press Release Distribution, Video Content, Local Broadcast Media

Proposal Overview

This 12-week awareness and engagement campaign is designed to elevate the visibility of the Nevada Rare Disease Advisory Council (NV RDAC), increase statewide participation in the 2025 Needs Assessment, and lay the groundwork for future rare disease advocacy and policy impact.

As the only council dedicated to representing the voice of Nevada's rare disease community, our success depends on gathering input from families, providers, and stakeholders across all regions of the state. This campaign will ensure that the Needs Assessment reaches the audience it's meant to serve—and that their insights translate into meaningful change.

We are seeking NV RDAC council approval to launch this campaign beginning August 2025.

Campaign Objectives

- Maximize participation in the statewide Needs Assessment
- Raise public and policymaker awareness of NV RDAC's work and mission.
- Share stories and highlight unmet needs to inform future recommendations.
- Engage new advocates and partners for long-term impact.

12-Week Strategic Content Plan

The following phased plan outlines social media, email, press, video, and broadcast outreach to be deployed over the campaign:

Weeks 1–2: Campaign Kickoff – What is NV RDAC? What is the Needs Assessment?

- Facebook Post: Graphic + Link to Survey – "Your Voice Matters"
- LinkedIn Article: "The Power of Your Voice" by Annette Logan-Parker
- Email Outreach: Launch Announcement
- Press Release: Statewide Launch
- Video to Film: Welcome message from Annette introducing the campaign.
- Broadcast Media: Begin outreach to secure spots on local news channels in both Northern and Southern Nevada to promote the campaign launch.

Weeks 3–4: Why This Assessment Matters

- Infographic Post: “How Your Input Drives Policy”
- Patient Testimonial or Story Post
- LinkedIn Article: “From Data to Action”
- Video to Film: Family or patient voice highlighting prior impact.

Weeks 5–6: Highlighting NV RDAC’s Mission

- Carousel Post: “What Does NV RDAC Do?”
- Member Spotlight Post
- LinkedIn Article: “Meet the Council”
- Video to Film: NV RDAC members discussing their roles.

Weeks 7–8: Real Challenges in Nevada

- Barriers Infographic Post
- Provider Testimonial Post
- LinkedIn Article: “The Hidden Struggles of Nevada’s Rare Disease Community”
- Email Update + Survey Reminder
- Video to Film: Provider panel on access issues

Weeks 9–10: How to Get Involved

- “3 Ways to Join NV RDAC’s Mission” Post
- Advocate Voices Post
- LinkedIn Article: “Becoming an Advocate in Nevada”
- Video to Film: Young advocate sharing their journey.

Weeks 11–12: Final Push and What’s Next

- Final Reminder Post + Survey Link
- “Stay Connected with NV RDAC” Post
- LinkedIn Article: “Beyond the Survey”
- Final Email Reminder
- Press Release: Last Call for Participation
- Video to Film: Thank-you message and campaign wrap-up.
- Broadcast Media: Final-week TV appearances to drive last-minute survey submissions and promote upcoming NV RDAC efforts.

Additional Article Topics to Expand Campaign Content

To enhance engagement and provide deeper insights into the rare disease landscape in Nevada, we propose developing additional articles around the following themes:

1. A Day in the Life: Living with a Rare Disease in Nevada
2. Why Representation Matters: Building a Rare Disease Policy Voice in Nevada
3. Closing the Gap: How Nevada Can Improve Rural and Underserved Access
4. Rare Disease Doesn’t End at 18: Transitioning from Pediatric to Adult Care
5. Genetics & the Future of Rare Disease Diagnosis in Nevada
6. Spotlight on Rare Disease Providers in Nevada
7. From Data to Policy: What We’ve Learned from Previous Needs Assessments
8. Rare Disease & Medicaid: Breaking Down Barriers to Access

These pieces will be rolled out on LinkedIn and Facebook and can be supplemented with video content or shared through media partners and advocacy networks.

Follow-Up Engagement Activities Through World Rare Disease Day (February 2026)

To build sustained engagement and culminate in a high-impact observance of World Rare Disease Day, the following activities are proposed for February 2026:

World Rare Disease Day 2026 – Event & Media Plan

- Theme: “Shining a Light on Rare – Nevada’s Commitment to Every Patient”
- Date: Friday, February 28, 2026 (Observed event dates may vary for hybrid participation)

Planned Activities:

- Host a hybrid statewide awareness event with in-person gatherings in Las Vegas, featuring speakers, patient stories, and stakeholder engagement.
- Secure a Governor’s Proclamation declaring World Rare Disease Day in Nevada.
- Launch a statewide media campaign across radio, print, and digital outlets spotlighting rare disease champions, Nevada-specific data, and unmet needs.
- Film and release a campaign video wrap-up + patient tribute montage, celebrating the work done and highlighting stories from across the state.

These activities will serve as both a closing chapter to the 2025–2026 campaign and a launchpad for new initiatives leading into the next legislative session.

To sustain momentum and deepen impact following the 12-week campaign, NV RDAC will continue community engagement and awareness efforts through February 2026. Proposed monthly activities include:

September 2025:

- Publish Needs Assessment summary findings and key insights.
- Launch "What We Heard" social media mini-series highlighting quotes from participants.

October 2025:

- Host virtual town hall for providers and advocates to discuss initial findings.
- LinkedIn Article: "Bringing Data to Life: What We're Learning About Rare Disease in Nevada"

November 2025:

- NV RDAC Council Member Panel video release: "What's Next for Nevada's Rare Disease Strategy?"
- Begin planning outreach for 2026 legislative session priorities.

December 2025:

- Share patient and caregiver reflections from the year.
- Release "Year in Review" visual report featuring campaign milestones and impact.

January 2026:

- Publish 2026 Policy Preview: NV RDAC Recommendations for Rare Disease Action
- Begin push for World Rare Disease Day collaborations with state agencies and community partners.

February 2026 (World Rare Disease Day):

- Host hybrid community event in Las Vegas.
- Coordinate Governor's Proclamation recognizing World Rare Disease Day
- Launch media campaign spotlighting Nevada rare disease champions.

What We Need from the Council:

- Approval of proceeding with campaign content development and scheduling
- Input on video participants, spotlight nominations, or regional targets

- Suggestions for strategic partners and cross-promotion opportunities
- Support for media outreach efforts, including identifying local media contacts in both Northern and Southern Nevada